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Trust, Targets and Teenagers:

The negative impact of the audit culture combined with the medicalisation of adolescence on young people with diabetes

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Abstract

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Abstract

Objective: To examine the value of 'trust' in the delivery of patient centred care for young people with Type 1 diabetes.

Design: A longitudinal, quantitative study using semi-structured interviews and observation of consultations using the constant comparative method.

Setting: Seven clinical centres in three Health Boards in Scotland.

Participants: Nineteen health care professionals and 65 young people.

Results:

Conclusions: Two distinct barriers (the audit culture and medicalisation) interfere with the establishment of long-term reciprocity between health care professionals and young people with diabetes, which diminishes the development of trust based relationships.

To improve the reciprocity necessary for maintaining these long-term relationships requires both an appreciation of these barriers and a change in management strategy to nullify their impact.

Introduction

Effective communication between doctor and patient is a critical component of high-quality care and a physician's credibility has a significant effect on treatment outcomes. Since the early 1980s developments in health service policy and practice have prompted careful evaluation of the nature and importance of trust relationships in health care contexts [1,2]. Relevant here is the conceptualisation of interpersonal trust, commonly described as one person's expectations of another's good intentions, expertise and behaviour on their behalf [3]. The foundation of long-term trust is underpinned by 'generalised reciprocity' which describes transactions that occur between participants in highly trustful, long-term relationships to facilitate common goals and to harness co-operation between people [4,5]

Trust, therefore, is accepted as the basis of effective patient-centred care, and is particularly so in diabetes, which depends on self-management by the patient following advice from their Health Care Professional (HCP). Adolescents are a particularly vulnerable group, who require their relationship with their HCP to be based on mutual trust. An increased recognition of the rise in mortality and morbidity associated with poor management of type 1 diabetes in this age range [6], and a greater emphasis on high quality services for children and young people (The National Service Framework 2005 [7]) prompted this study to investigate the part that trust plays in effective communication between young people with this long-term condition and their HCPs and to explore the barriers that may interfere with these relationships.

We undertook a unique interdisciplinary study (anthropology, management and medicine) as an action research project, to examine young people's and health professionals' experiences of working together in centres across Scotland to examine the barriers to trust. Our interpretation draws on a previous study, 10 years earlier, with many of the same health professionals, but a different cohort of young people [8,9]

allowing a comparison of "stories", and enabling an interpretation of patient centred

care in response to health service policy over time.

Participants and Methods

Participants were recruited from seven out-patients clinics in three Health Boards in Scotland. We used purposive sampling methods (that is, we intentionally sought to interview subjects with certain characteristics) to ensure a range of demographic variables and experiences: equal sex ratio; range of glycaemic control as defined by glycated haemoglobin (HbA1c%); duration of diabetes. Centres were invited through the Scottish Study Group for the Care of the Young with Diabetes (SSGCYD) and three were chosen to represent the social demography of Scotland. Comparison of the demographic data from each Centre using Carstairs scores revealed no differences. All subjects were white Caucasian. The researchers (AG and PM) were blind to clinical outcomes of the patients.

Young people (n=65; age 13 to 19 yr.: HbA1c mean xx.x; range x.x to y.y; all treated with daily insulin injections or insulin pump) from the Centres participated in the study after agreeing to be observed together during consultations with their HCP (n=19) (See table 1). Both participants were then interviewed separately. Both agreed the interviews to being tape recorded. Observation of the consultations and further observations of the clinic routine and working practice allowed contextualisation of both participants accounts.

The study was approved by the respective LREC for each Health Board.

Analysis was based on the constant comparative method, and the HCPs and young people's accounts were analysed separately [10]. AG developed the thematic frameworks. Each transcript was repeatedly inspected before applying open codes to describe each unit of meaning. Through comparison across transcripts, the open codes were developed into higher order thematic categories to provide a framework for coding the transcripts. AG continually checked and modified the framework categories to ensure an adequate fit with the data, and SG independently validated the assignment of the

data to the categories. Case study analysis [11] was used to generate the key features from the two groups, i.e. the young people and HCPs.

The theory of reciprocity and trust allowed us to critically examine [12] the place of diabetes in the lives of both the young people and their HCPs and to acknowledge its variable significance and demands on their relationships with one another. Our aim was to elucidate the deeper meanings that inform the participants' conversations and behaviour and thus, to allow for their subjective experiences to inform the analysis and explanation [13]. While we are grateful to the generosity of the participants in the field, the following account rests on our interpretation of the data and is framed by our different disciplinary approaches.

Previously in 1998 we undertook a similar qualitative study using the same methodology with 30 young people (aged 13-18) with Type 1 diabetes and 15 HCPs across several centres in Scotland, again directed by the SSGCYD [8, 14, 15]. While both the patient and HCP cohort were different subjects from this second more recent study, clinical management was under the NHS care policy for diabetes of the day. While not designed as a longitudinal study, comparison of the interpretations of this qualitative data allowed a contrast of "stories" and the longitudinal aspect contributes to the overall development and analysis by providing a more in-depth interpretation of the notions of change and its meaning for the participants.

Results

Two separate themes emerged as barriers to the development of trusting relationships between adolescents with type 1 diabetes and their HCP's: i) interference by the process of clinical audit, and ii) the medicalisation of adolescence as an additional condition. These barriers appeared both to diminish trust between staff members in the different centres and negate efforts made by HCPs to engage young people in patient centred care.

The process of clinical audit and its impact on trust.

Young People's accounts of diabetes audit

Evident was the frustration felt by patients with HCPs pre-occupation with diabetes outcome measures (e.g 'glycated haemoglobin - HbA1c'). Many felt that staff were too concerned with medical notes and adding data to their computers, rather than listening to their stories. Blood measurements were too abstract for most and revealed nothing of the '*ups and downs*' of their daily lives. What they wanted was time to speak about the specifics of their situation and how this impacted on coping with diabetes.

Young person: *'They're nice, but you have this feeling that they don't really see you, all they see is the number* [blood glucose reading] *in your notes. It doesn't matter what's been going on in your life, that's how you're judged, as a number.'*

Many of the young people faced a range of personal and familial challenges that were either prior or subsequent to having diabetes. These included issues around sexuality; schooling and higher education (particularly the stress associated with continual assessment and exams); economic hardship and redundancy; parents divorce; peer friendships and relationships with adults.

Young person: *' 'They* [staff] *think it's* [diabetes] *the main thing going on in your life, but it's not, it's just a tiny part.'*

A number were sympathetic with the pressures health professionals were under to improve their management.

Young person: *'It's not their fault…they're under a lot of pressure, but it's the wrong way around, because they've got to focus on the end result, your* [blood glucose] *control, but for me I've got to start at the beginning and juggle everything in my life with diabetes.'*

The inappropriateness of staff viewing diabetes outcomes as the central issue in their patients' lives was, many felt, imposed upon them in a number of the clinics. All young people spoke about feeling more comfortable with staff that took a holistic approach to diabetes. In other words, those that appreciated that diabetes was just one of the many variables affecting youth on a daily basis. Thus, they appreciated staff that acknowledged them in the waiting room by remembering their name, reassuring them in the face of good or bad news and *warming them up,* by asking them about themselves and then relating this information to strategies to help them manage diabetes.

Interviewer: *'What do you mean by warming you up?'* **Young person:** *'[Laughs] it's a bit like sex, it's better if you get to know each other first…so it's better to do that in the clinic, so you don't go in* [to the consultations] *and they ask you about your diabetes control straight away.'*

The continuity of seeing the same member of staff at each appointment helped to win their trust and allowed them time to build-on the stories of their diabetes at each appointment with the same person. Solidarity and reciprocity between young people and HCPs promoted a sense of claiming or owning health-care relationships, as a two-way process, suggestive of intimacy and familiarity between people. Disowning or non-attendance was seen as a one-way process expressing low self-esteem, anger, disillusionment and resolve.

HCPs accounts of diabetes audit

Implicit in the interviews HCPs were the changes that clinical audit brought to their relationships with young people and other colleagues. On the one hand, assessment was important to not only protect patients from poor quality health care, but to protect themselves from litigation. On the other hand, the challenges of balancing these procedures with rising patient numbers and limited resources had shifted the focus away from the patient and onto the health care organisation. These difficulties were even more pertinent with a group known to be '*especially challenging*' i.e. adolescents. While most agreed that national policy on 'patient-centred care' was right, most were frustrated by the lack of advice on how to implement such relationships with this difficult age group. Moreover, remit of patient-centeredness, from the policy perspective, appeared more to do with improved outcomes than about how to work with patients to achieve them.

 HCP: *"No one would disagree that we need to improve diabetes outcomes, but that doesn't just happen naturally. You've got to work hard at gaining their respect; it takes energy to build the chemistry you need between you to make it work. They've got to feel it's worth doing all the things we ask them to do (insulin injections, blood tests, diet, exercise). I doubt half of us could do what we ask of our patients, If I'm honest. It takes an incredible amount of trust to get them to do what you ask, day in and day out, for the rest of their lives."*

For HCPs, the greater focus on outcomes, and the regulatory procedures to achieve them, was only one side of the story. The advice for how to achieve patient-centered care, to achieve improved diabetes measures was missing. In fact, the emphasis on collecting data took time away from the time needed to work with patients to achieve these targets. Regulation for some therefore, had rendered the intimacies of their

9

relationships with patients invisible; representing them instead as complex audit systems and mounting paper trails.

HCP: *'It's a good thing* [audit], *definitely, but I think it's got a bit out of hand. There's so much paperwork now it makes it more difficult to focus on the patients.'*

HCP: *'It's becoming all about ticking boxes not patient-centred…and um, sometimes it's overwhelming and I wonder where the human part, the patient-carer relationship has gone.'*

An unexpected finding relating to regulation however, not evident 10 years earlier, was the apparent breakdown of trust between the staff in the different centres. With this, the climate of constant change and re-organisation in the NHS added to feelings of *'war-weariness'* and demoralization.

HCP: '*Sometimes you wonder what's the point* [in changing] *it will only change back again in a few years. I've been in it* [the NHS] *long enough to know these things are always cyclical.'*

Most HCPs believed that diabetes services were already an exemplar of good standards and a '*pathfinder*' for other services and as such, much audit was unnecessary. The creation of '*league tables'* had challenged the openness between centres, and the opportunity to share information and swap stories, which appeared to be replaced with feelings of miss-trust and competition. For a small number however, the positive side of audit far outweighed these negative issues. For these, clinical governance was associated with public responsibility and the morality of health provision, and any discord would be overcome by the powerful ethos of good-will, solidarity, altruism and trust in and between clinicians, to make sacrifices to advance medicine for the good of the patient.

HCP: *'I feel passionately that we're moving in the right direction. It's an uncomfortable move for a lot of people, I know that. I sit on the XX Standards Board and its*

difficult...we're not used to it [audit] *as a profession. But to me it's worth it to advance diabetes care. That's got to be a good thing.'*

A larger number of staff, reflected on the negative effects that audit had in marking centers out against one another, and altering the delicate system of support, camaraderie and trust between the members in the different centers:

HCP: *'I entered medicine to help people. The league tables have changed that ethos. I'm having to be an expert accountant and manager too because everyone is competing and out for themselves.'*

For many, particularly doctors, governance was viewed as a top-down system that altered the balance of professional autonomy and independence

HCP: *'We're all fighting for money for our little patch of expertise so you're not going to buy into something if you don't think it's going to fit your needs. To give you an example, I'm interested in retinopathy services in the community, but my colleague in X is more involved in foot care. If you don't feel what you're being asked to do will give you something personal in return then you just end up paying lip service to the system.'*

However, another clinician, a nurse manager described medical independence rather differently:

HCP: *'Doctors see themselves as more independence than us* [nurses]*...and trying to organise them can feel like herding cats.'*

For a small number, getting involved on the regulatory committees was a move to reintroduce a sense of agency and ownership. Their involvement allowed these to feel they were moulding the system to the specifics of the diabetes services, rather than merely being on the receiving end of it. For these, pragmatic collusion was realistic and a case of:

HCP: *'If you can't beat them it's better to join them.'*

Committee work also offered respectability, professional development, and the possibility of merit awards and importantly, some time out from the pressurised '*coal-face*'. Many spoke about feelings of professional burnout and the tedium of looking after a long-term illness that was difficult to control.

HCP*: 'If I'm honest the* [committee] *work provides a fillip from the daily grind of the work.'*

But time off for some left others to cover the clinical load. Moreover, the product of these committees could be more regulations and paper trails for those on the coalface.

HCP: *'Ok, we do need to be regulated, everyone would agree with that, but the more they work on these committees the more they send down to us, and we're the ones that have to try to cope with the mountains of paper work.'*

This was particularly important for nursing staff and other affiliated professions who had less opportunity to join medical committees, and which may have in part accounted for the high levels of sick leave among them. Partaking in governance initiatives therefore, appeared to be an opportunity for some and for these was framed within a discourse of responsibility, respectability and ethical systems of health care. For those more sceptical, regulations enforced hierarchical relationships between mangers and health professionals; reinforced structures of competition; often embedded within a no-can-do environment of fractured collegial relationships that many felt wore away at staffs' energy levels and drive to be creative and entrepreneurial.

Medicalisation of adolescence and its impact on trust.

Young people's accounts of adolescence

Evident was young people's frustration when HCPs blamed their '*poor control*' on being adolescent. Seeing someone in terms of their grouping (as with race and gender) and in this case with negative associations, ignored the importance of their individual

existence and the particularities of their young lives when faced with multiple situations and tasks. Thus, seeing adolescence as a key issue in their lives, and the reason for their '*poor control*', was a notion that sat uncomfortably with most. For young people, poor control was complex and made more so when faced with puberty, a time when there was a pressure placed on them by adults to '*stand on their own two feet*' and manage diabetes alone. A number of young people, particularly young men, were more likely to keep quite about the support they received from their families, especially their mothers, for fear they would be labeled a '*mummy's boy.*'

Young Person: *'There's a lot of pressure on you to do everything yourself, but I don't think that's normal. It's normal to want people to support you if you've got a problem, and that doesn't change just because you're a teenager.'*

Normative interpretations of adolescence as an age-based disorder drew attention away from the other significance challenges in their lives. Moreover, while many HCPs related their management behaviour to *risk-taking*, and part of being adolescent, young people were more likely to see themselves as master negotiators; balancing the complexities of their diabetes with their everyday lives.

Young Person: *'It's like they think you've got two illnesses to control: being diabetic and being adolescent."*

Young Person: *It's not like being a teenager makes me do crazy things with my control, it's more about just growing up and having to handle not having a hypo* [hypoglycaemia, or low blood glucose] *and falling over in front of your friends.'*

HCPs accounts of adolescence

For the majority of HCPs, looking after adolescents brought with it a set of inherent determinants that were felt to predispose patients to take dangerous risks with their bodies (e.g. omitting insulin, running blood sugars high) which started, as one HCP explained it, the '*time-bomb*' of micro vascular changes and the potential for serious

complications and the deterioration of long term health. Embedded within these beliefs was the idea that 'normal' adolescents were naturally deviant; expressed through poor control and contributing to the belief that 'good controllers' were somehow abnormal. As one HCP described it: *'You expect teenagers to have poor control, it's part of their make-up at that age. In fact, in my experience adolescents with good control are abnormal; I would say even a little bit worrying."*

Interviewer: 'How do you mean?'

HCP: *'Well for example, they have a good relationship with their parents and get on with adults and want to do well. In my experience they can be a bit obsessive; over anxious. One young man used to bring a clip board with all his results on including everything he'd eaten.'*

Interviewer: '*You don't want them to do that?*'

HCP: *'We don't want to make them neurotic, no.'*

Implicit in these ideas was the notions that the rigorous behaviour they might welcome in an adult patient was deviant in adolescents. Moreover, poor control, despite its long-term effects, was preferable to young people becoming over anxious.

For staff, patient-centered relationships ('befriending them') were essential to over-ride any rebelliousness and anti-adult authority behaviour, and underpinned their attachment to staff and their desire to attend clinic appointments. The rationale here was that if their behaviour could not be changed at least staff could keep an eye on any physiological damage that might occur with the hope of nipping any early signs of deterioration in the bud. Encouraging this patient group to attend however, required a particularly high level of energy.

HCP: *"I think you've got to be a certain type of person to want to work with teenagers. It can be a thankless, soulless task and it can feel as if you're banging your head against*

the wall. And it's not about knowledge, they all know an incredible amount about diabetes and what they're doing to themselves…you have to be incredibly patient because most of the time its a case of building a relationship with them to keep them on board until they're older and want to start looking after themselves."

Interviewer: *"Why do you think that is?"*

HCP: *"I don't think anyone has the answers, but in my experience it seems to be something to do with ownership of their own lives and taking on responsibility, like having a partner, children and having a mortgage. Our responsibility is to keep them as well as possible until they have this shift in perspective."*

Discussion

The delivery of patient centred care is based to a major degree on the successful communication between the patient and their HCP. Trust between these individuals is a mandatory component of effective communication. Our study which explores the interactions and accounts of young people with type 1 diabetes and their HCPs reveals two distinct themes which appear to be barriers to the development of trusting relationships: the audit culture and medicalisation of adolescence.

Our first theme elates to the shift from self-regulatory approaches in medicine to a government-driven, interventionist style, are inherently bound up with the experiences of participants. Yet the importance of these experiences and the impact they have on patient-centred care is rarely featured in the formalistic approaches in health care evaluation. While, a small number of HCPs were willing to put their trust in clinical audit, the majority gave accounts of how patient-centred care had become inextricably bound to bureaucracy [16] Implicit in their narratives was their concern to achieve quality care in a way that allowed them to maintain their enthusiasm for working with this challenging age group. What was frustrating for many was the obvious miss-match between assessing young people's physical health and their obvious concerns also for their social and psychological well-being, which involved employing hunches, intuition and empathy, but which was impossible to audit. Consequently, management systems ignored the time and energy needed for reflection and creativity to nurture trusting relationships based on reciprocity. Moreover, the drive for league tables between sites fractured the delicate balance of trust between HCPs required to preserve their reputations, irrespective of centre outcomes.

Matching this, young people spoke of HCPs' preoccupation with checking their diabetes measures. This implied that diabetes was the event that defined their young lives, rather than part of an ongoing social process that was played out in a complex

16

variety of ways, over time. From this perspective, HCPS' preoccupation with diabetes outcomes increased their negative attitudes to young people, and underpinned their identity as a homogeneous group of risk-takers, who were unsuccessful managers of diabetes. Against the powerful discourse of clinical audit, it can be difficult to make a case for the role of trust and reciprocity in long-term illness, and particularly so when target setting, key to surveying and measuring performance, is the basis of governing at a distance and where the intimacies of relationships seem unnecessary [17]. Indeed, governance, by its very nature of measurements and monitoring, is put in place to override any reliance on personal trust. In fact, the shift from inter-personal trust between people, to in-direct trust in system and organisations leads to relationships of dependency where trust is not reliant on personal experience. Yet attempting to renegotiate these relationships between young people and HCPs can create mistrust and the need for constant reassurance to encourage young people to attend clinics so that measurements can be taken. The counterbalance does not mean the abandonment of regulation, but the recognition that inter-personal trust should never be over-ridden by external drivers in the NHS. While the time put into interdependent relationships may seem costly, the investment is crucial to underpin the sustainability of a quality culture in the NHS.

In addition, clinical audit clearly had an impact on the relationships between HCPs. For many trust between colleagues was the bond that underpinned common notions of working together with an illness where burnout and '*diabetes fatigue*' was common and where limited resources, rising patient numbers and sub-optimal outcomes in adolescents contributed to the demoralisation of both young people and HCPs. Trust offers a way of containing these difficulties, when faced with this high risk illness, by facilitating disclosures by the young person, and the hope of encouraging behavioural changes that facilitated the successful management of diabetes [1].

The second major theme revealed was the medicalisation of adolescence i.e. viewing adolescence as a medical problem rather than a normal developmental process. This compounded the negative views expressed by HCPs of diabetes in this age range, and made young people feel they were being treated as if they had two illnesses: diabetes and adolescence. This acted as a "double whammy".

The need to contextualise adolescence in a way that did not define it as the key life experience that determined their chances is a theme pertained to in the Scottish Diabetes Framework [16] but appeared less well attended to in the narratives of many of the HCPs we spoke with.

It is important to recognise, therefore, are the power relations inherent in medical practice, particularly so in the case of adolescence[17]. Young people from their accounts preferred to see themselves as major actors in thinking about trust and how its meanings and practice are shaped in relation to co-operation to achieve common goals in the management of illness. Adolescents, contrary to popular belief, seem able to shape trusting relationships as well as HCPs.

When trusting relationships with HCPs evolve over time, based on sustained, attentive and supportive health care, they are perceived positively. However, where these features are missing, or inconsistently applied, such as being referred to different or inexperienced staff at clinic, the regimen of management and clinic attendances may become a trial for young people. Our study reveals that the task of sustaining diabetes management over many years is a particular challenge for young people and that disadvantaged relationships with HCP, caused particularly by the barriers of clinical audit and medicalisation of adolescence, may outweigh the efforts young people and their support networks make towards their rigorous self-management of diabetes.

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Table 1: Demographic details of subjects

Regions	Centres	Patients and HCPs interviewed	
Region 1 (I Centre)	1 Teaching Hospital	10	patients
		4	*health professionals*
Region 2 (4 Centres)	2 Teaching Hospital	10 x 10 patients =20	
	1 District General Hospital	10	patients
	1 Cottage Hospital	3	patients
		11	*health professionals*
Region 3 (2 Centres)	1 Teaching Hospital	10	patients
	1 District General Hospital	10	patients
		4	*health professionals*